ORIGINAL ARTICLE

REVISTA ENFERMAGEM ATUAL IN DERME

PERCEPTION OF VULNERABILITY BY THE FAMILY IN SCHOOL INCLUSION OF CHILDREN WITH CHRONIC CONDITIONS

SITUATION OF VULNERABILITY PERCEIVED BY THE FAMILY IN SCHOOL INCLUSION OF CHILDREN WITH CHRONIC CONDITION

SITUAÇÕES DE VULNERABILIDADE PERCEBIDAS PELA FAMÍLIA NA INCLUSÃO ESCOLAR DA CRIANÇA COM CONDIÇÃO CRÔNICA

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ABSTRACT
Objective: To know the situations of vulnerability perceived by the caregiver/family member in school inclusion of children with chronic conditions. **Methods:** Qualitative study carried out through interviews with 10 family members/caregivers of children with chronic conditions, from June to August 2018 in a municipality in southern Brazil. Thematic analysis was used to analyze the information. **Results:** Several situations of vulnerabilities experienced by families were found, upon the insertion of the child in school, such as the performance of procedures and medication to the child by education professionals, the lunch offered at school, the difficulties experienced by the child with chronic health condition. **Final considerations:** Health and education professionals have to pay close attention to families/caregivers and children with chronic conditions, aiming to know the situations of vulnerability experienced and favoring the establishment of support networks to improve the quality of life.
Keywords: Family; Child; Chronic Disease; Pediatric Nursing; Mainstreaming, Education.

RESUMEN
Objetivo: Conocer las situaciones de vulnerabilidad percibidas por el cuidador/familiar en la inclusión escolar de niños con condición crónica. **Método:** Estudio cualitativo realizado a través de entrevistas con 10 familiares/cuidadores de niños con enfermedad crónica, de junio a agosto de 2018 en un municipio del sur de Brasil. Para el análisis de la información se utilizó el análisis temático. **Resultados:** Se encontraron varias situaciones de vulnerabilidades vividas por las familias al momento de la inserción del niño en la escuela, como la realización de procedimientos y medicamentos al niño por parte de los profesionales de la educación, el almuerzo ofrecido en la escuela, las dificultades vividas por el niño frente a condiciones crónicas de salud. **Consideraciones finales:** Es necesario que los profesionales de la salud y la educación presten atención a las familias/cuidadores y niños con condición crónica, con el objetivo de conocer las situaciones de vulnerabilidad vividas y favoreciendo el estabelecimiento de redes de apoyo para apoyar la mejora de la calidad de vida.
Palabras-clave: Familia; Niño; Enfermedad Crónica; Enfermería Pediátrica; Integración Escolar.

RESUMO
Objetivo: Conhecer as situações de vulnerabilidade percebidas pelo cuidador/familiar na inclusão escolar da criança com condição crônica. **Métodos:** Estudo qualitativo realizado por meio de entrevista com 10 familiares/cuidadores de crianças com condição crônica, nos meses de junho a agosto de 2018 em um município do sul do Brasil. Para analisar as informações utilizou-se a análise temática. **Resultados:** Constataram-se diversas situações de vulnerabilidades vivenciadas pelas famílias, ao inserirem a criança na escola, tais como a realização de procedimentos e medicações à criança pelos profissionais da educação, a merenda oferecida na escola, as dificuldades vivenciadas pela criança frente às condições crônicas de saúde. **Considerações finais:** É necessário que os profissionais de saúde e de educação tenham um olhar atento às famílias/cuidadores e às crianças com condição crônica, visando conhecer as situações de vulnerabilidade vivenciadas e favorecendo a constituição de redes de apoio para suporte na melhoria da qualidade de vida.
Palavras-chave: Família; Criança; Doença Crônica; Enfermagem Pediátrica; Inclusão Escolar.

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INTRODUCTION

All human beings are vulnerable, for the simple fact of being alive, predisposed to uncertainties of this condition, and the knowledge of vulnerability comes from the uniqueness of each individual and the possible situations to which they may be exposed[1-2]. Vulnerability situations can be classified into three elements: the individual, social and programmatic axis. The first refers to individualities of each person, from their health conditions and limitations or knowledge about their rights; the social axis includes social and economic conditions, accessibility to information and guarantee of human rights; and the programmatic axis refers to public policies and the way they are articulated to meet the different situations that people may experience[3].

The chronic health condition is related to the way it is seen and treated by society, as well as its organization for the inclusion of children, adolescents, their caregivers and family members, which sometimes generates social and emotional issues, in addition to other factors that enhance situations of vulnerability[4]. In this way, care must take place in different environments, inter and transdisciplinary, with a view to promoting and comprehensive care for this population, opposing the health needs and the presence of gaps in support and social network, for the daily demands[5].

The school is an important environment for socialization and social insertion, where children and adolescents can interact with their peers and teachers by talking, making friends, discussing and developing skills that favor interaction with other children and with the social environment[6-7]. Children and adolescents with chronic conditions have specific needs in the classroom, requiring a qualified professional to perform the function, with essential tools to meet their particularities, enabling learning conditions and guaranteeing the right to education and socialization in school life[8].

In this context, it is important that there be articulation between educators and health professionals, aiming to contribute to the school inclusion process, especially for children with high demand for care. A study points to a gap in scientific production in the health area, which reveals the configuration of the articulation between health professionals, educators and family members in promoting the school inclusion of children with chronic conditions and in meeting their care demand[7].

The importance of the school is evident, and for the insertion to occur effectively, the participation of the family in the school environment and in areas of education and health is fundamental. The family is considered an ally to make these practices viable, so that their special health needs are not an obstacle to their coexistence and socialization[4].

Attention, listening and knowledge sharing between professionals and family members allow the strengthening of the bond, contributing to the implementation of sensitive, meaningful and effective care[9]. In this context,

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it is essential to understand the needs of children with chronic conditions and their families, in order to obtain a greater understanding and design strategies capable of minimizing the situations of vulnerability to which they are exposed[10].

Therefore, the guiding question of this study was elaborated: What are the situations of vulnerability perceived by the caregiver/family member in the school inclusion of the child with a chronic condition? With that, the objective was to know the situations of vulnerability perceived by the caregiver/family member in school inclusion of children with chronic conditions.

METHODS

This was an exploratory descriptive qualitative study, developed in a municipality in the south of Brazil, from June to August 2018, with family members who provide direct care to children with chronic health conditions. It is noteworthy that the research followed the criteria that involve quality and rigor in qualitative research according to the Consolidated criteria for reporting qualitative research[11].

Information was collected by an interview containing questions about the characterization of participants and about their perspective on situations of vulnerability in school inclusion of children with chronic conditions. Interviews were individual, in a private place, with the participants' home as a scenario, as well as the workplace and the health service in their municipality, with an average duration of 40 minutes. A voice recorder was used to record the statements, which were later transcribed in full manually.

Participants were intentionally selected from the database of the Multicenter Research Project - Vulnerabilities of children and adolescents with chronic diseases: care in a health care network. For this research, all family members/caregivers of children with chronic conditions hospitalized in Pediatric Units of Hospitals in the studied municipality were invited, although many of them lived in surrounding cities.

The inclusion criterion was being a family member responsible for the care of a child with a chronic condition. Family members of children in palliative care or in critical life situations and family members under 18 years of age were excluded. To determine the number of participants, the saturation criterion was used, that is, when it was concluded that the collection of new elements and the coding of information collected would not provide more elements to deepen the theorization, which in this study corresponded to 10 participant[12]. Thus, it was not necessary to add new information, since it would not change the scope of understanding of the phenomenon to be studied.

Information collected was analyzed following the steps of the Thematic Analysis, consisting of six steps[13]: a) Familiarization with the data; b) Data encoding; c) Grouping into themes; d) Review of themes, construction of the thematic map; e) Definition and attribution of

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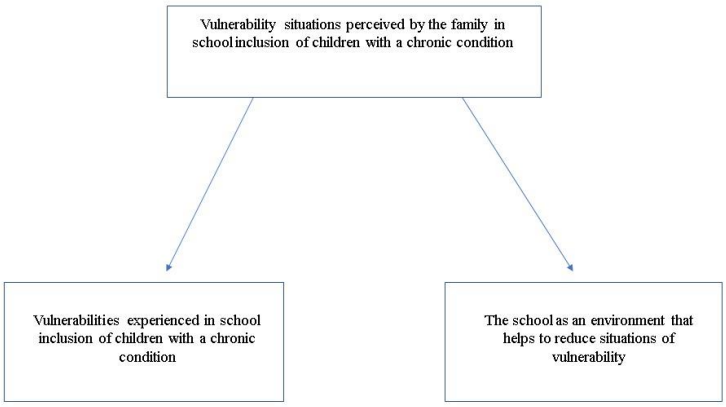
names to themes; f) Production of the report. In order to interpret the results, vulnerability situations were evaluated, according to the triad of individual, social and programmatic elements, making it possible to observe most factors involved in these situations[3].

The thematic map prepared is shown below:

Figure 1 - Thematic map.



Source: The authors

For this study, the ethical precepts determined by Resolution 466/12[14] were respected. Therefore, participants were invited through the Informed Consent, in which their voluntariness was made explicit. Data were collected after the research project was approved by the Research Ethics Committee under opinion number 2736019, CAAE 90904418.3.0000.5316.

The anonymity of participants was respected, using the consonants "FM", "FP", "FVó" or "FVô", respectively for Family Mother, Family Father, Family Grandmother or Family Grandfather, followed by an increasing number referring to the order of interviews, e.g. "FM1" to name them.

RESULTS

Participants were ten caregivers/family members, constituting eight families of children with chronic conditions. Of these, seven were mothers, one father and two grandparents. The family members were between 27 and 58 years old, in relation to schooling, six had incomplete elementary school, three had completed high school and one had completed higher education. As for the family income, it was between R$290.00 (from government aid received by the family) and R$2,000.00.

The children were aged between five and nine years, being in elementary school and one in early childhood education, with the following

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diagnoses of chronic conditions: asthma, diabetes mellitus, epilepsy, nephrotic syndrome, Crohn's disease, Hirschsprung's disease, hyperactivity and schizophrenia. In two cases, the children had more than one associated chronic condition.

Vulnerabilities experienced in school inclusion of children with chronic conditions

Situations of vulnerability experienced in school inclusion of children with chronic conditions are related to various circumstances, such as the concern of family members with the specific care needed, lack of professionals to meet the demands of these children, dietary restrictions and leaves resulting from child hospitalization.

Family members mentioned that this inclusion causes concern, as it becomes difficult to have control over the necessary care:

> *My real concern is if they are looking at her, if she is not feeling sick and no one is watching. It is a difficulty of mine, of feeling. The teacher has many other children to take care of and look, and what if she doesn't see that* [daughter's name] *is breathing badly* (FM1).

> *I call the school every day, but of course, I remain nervous. The phone rings, I run out desperate* (FM6).

In these reports, the concern about leaving their children at school is identified. With the speech of FM1, it can be observed that she identifies the overload that the teacher has in the classroom, needing to be attentive and taking responsibility for all children.

One mother reported having changed her daughter to a new school because the school professionals did not understand the care required by the child's pathology. A grandfather also mentioned some clashes with school professionals due to the child's condition.

> *We changed schools, because at the school she was at, they didn't believe she had diabetes. My husband took the medical note and the other day the principal gave her a bag of candy. Then she took home the bag of candy. Two days passed; the teacher gave her a stuffed cookie* (FM6).

> *I went with him to school on the first day and explained to the teachers, because in the first days he went to school he couldn't make an effort, he couldn't run, he couldn't do physical education and he couldn't go to recess. So, I went there and talked to them, showed them what he was wearing. And they had to be careful. Until one day, they took pity on him and let him go to recess. Then they stuck a ball on him, on his belly [...]. Then she* [the teacher] *said that it was not right over the colostomy, that it was more on the side, but then he got scared and started crying. Then they called me so I could go and pick him up* (FM5).

> *We had a problem with physical education [...] the teacher objected. Then she insisted and insisted so much, I had to go to the principal, and said 'no, if she has the medical note, the teacher doesn't have to contest anything' [...]. The certificate was given by a physician, a professional* (FVô1).

The lack of a health professional in the school environment makes family members need to be attentive to the child's care and, in some cases, they need to go to the school to take care of the child, or arrange with the teachers so that these do.

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> *She is the only child who has diabetes at school. Now we take a device* [blood glucose test] *and deliver it to the principal if she complains* (FM6).

> *If I go there at three o'clock and her HGT is 300 or something, then I have to apply insulin. Or if she's really bad like that, then I'll bring her home. Sometimes they prefer that I bring her home than stay with her there* (FM7).

Some family members reported that the difficulties in including the child in school are related to the child's dietary restrictions, and many schools are not prepared to receive these children and adapt the school menu to their needs.

> *At school, at first, it was difficult because of food restriction* (FM4).

> *She takes a piece of fruit to school every day* (FM6).

> *The lunch depends, sometimes she takes it, when her blood sugar is low. Then I say 'my daughter, depending on what the school lunch is, if you want to eat, you eat'. But, she takes it from home, then she chooses, if she can eat that one, she eats it, if not, she eats hers* (FM7).

> *So, on the day there is food, at school they know, then they deliver it for her. Beans, rice, those things she can. Usually, school food doesn't use much seasoning, but the problem is that they use a lot of milk, cookies that contain milk* (FVô1).

> *Just now that we got with the school board to give her, from time to time, get her a snack food. If not, she doesn't eat. I went and said, because they told me that she had the right to a special lunch, I went and took everything they asked for, and they put a thousand and one difficulties. So, when I have it, I send her, when I don't have it, she goes without a snack* (FVó1).

Another factor also pointed out by family members was in relation to the child's attendance at school, due to hospitalizations during the school year.

> *Look, that time he was hospitalized he had a lot of trouble. Then I freaked out, I thought he was going to fail the year. There was no way he could move on to the next grade* (FM2).

> *Now this semester is a little difficult, as I used to spend a week there* [neighboring municipality] *and a week here. But the school principal is a wonderful person, she quickly understood her problem* (FM7).

> *We take the medical note, if she was hospitalized, and when we don't take the note we take the homework to the hospital, she does it, and I take it to the teacher. She did not fail any year due to illness* (FVô1).

> *There was a time when she was hospitalized and had a test, so she* [the teacher] *left it for when she returns, she would do the test. There was a teacher who even once went to take* [test] *there at the hospital* (FVó1).

Still in the context of the difficulties encountered, FP1 mentioned that the son came to suffer prejudice, due to the disease and its limitations. However, they were isolated cases and already solved together with the school, but that generated revolt in the child:

> *But he was very angry when he had that little bag. Sometimes he wanted to attack his colleagues, because someone messed with him* (FP1).

The school context can be a complicating factor for the care of children with chronic conditions. Living with other people who are often unaware of the restrictions that the

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chronicity can negatively influence the child, either through exposure to foods that are unsuitable for their health or through questioning and criticism about their health condition.

The school as an environment that helps to reduce situations of vulnerability

In the school inclusion of children with chronic conditions, despite experiencing different situations of vulnerability, there are also some potentialities, such as when the school assists in the care:

> *In this other school, thank God, she is being very well taken care of* (FM6).

> *Because he takes medicine at school. The teachers are the ones who administer it, so everything is well explained. They call me to ask anything [...] they helped me a lot* (FM4).

> *So, for me school is being wonderful* (FM7).

The provision of care by the school also favors the relationship between family members and the school:

> *I say, they know everything, all the care they have to take [...]. The relationship at school is good* (FM3).

School professionals also appear as support outside the school space, providing material support for the child and their family. As seen in the speech of FM6:

> *The principal of her school, she helps a lot. So much so that all the clothes that* [child's name] *is wearing today was given by her, most of the clothes I'm wearing were given by her* (FM6).

In the report of FM6, it is clear that the school helps not only in the education of the child, but also by providing material support, with clothes for both the child and their family.

DISCUSSION

The school is understood as an ideal scenario to provide the first experiences of socialization to children, as well as to expand them, being an important means for the development of autonomy. Thus, the school environment provides the essential process for the child to develop cognitively and socially[15].

In this context, it should be noted that children with a chronic condition face difficulties and special needs in the classroom, making it necessary for educators to be duly qualified to provide support for the learning of these children[8]. Therefore, it is necessary to invest in the preparation of teachers to meet the individual needs of children[8]. Therefore, it is important to include the school nurse, a professional trained to provide specialized care, in the educational context in an intersectoral and multidisciplinary team, this presence being a social and health need[16]. Furthermore, the inclusion of nurses in schools strengthens primary care through health promotion, allowing people to increase control over their health, increasing their skills and abilities, as well as favoring changes in social and environmental conditions[16].

The collaborative work of education, health and social care professionals is very important in schools, aiming to go beyond

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informative and diagnostic activities, with joint action, enhancing the specificities of each professional area to overcome the fragmentation of care provided to children and their families[17]. However, this is not yet an established reality, constituting a challenge for the implementation of inclusive education.

The school needs to enable the planning of inclusion strategies for children with chronic conditions and their families, in order to establish bonds and interactions, guaranteeing the right to education and socialization in school life with other children, in order to contribute so that these children can be potentially productive[8]. Thus, the school must be a space for integration and inclusion, this demands the preparation of educator professionals, since there are care that cannot be neglected[8].

In this study, the need for the mother to be present in the school environment was observed, providing specific care to the child with a chronic disease, often using personal inputs for this. The need for continuous support, even at school, hinders the employment relationship, as well as the performance of other activities, in addition to the high cost of treatment, which further increases the vulnerability of these families. Another study also identified the need for the mother to have to stop working due to the demands of child care, such as medical appointments, hospital admissions, exams and other treatments, in addition to the high costs of treating children with special needs, which impose the need to often having to seek resources with loans or other forms[18].

In this scenario, the disarticulation between education and health professionals disfavors the process of school inclusion of children with chronic conditions, and education professionals feel the need for guidance from health professionals, so that they can meet the care demanded by these children[7].

Based on these questions, a situation of vulnerability is identified in the individual, social and programmatic axis, due to the implementation of behaviors, in which mothers, in particular, come to exist only as caregivers of a child with a chronic condition, not being able to develop other roles, such as that of a woman and that of a worker. The social axis includes the living conditions of these caregivers and the changes in their daily lives. Finally, the programmatic axis places caregivers and children in vulnerable situations, because the health system does not offer prevention, control and assistance actions[5].

The concern, shown by family members/caregivers, regarding care for the maintenance of the child's health at school, could be minimized with the presence of the nurse at school, since this professional can work with families, children and school, developing disease prevention and health promotion in the school community. Decree 6286 as of December 2007 implements the Health at School Program, with the objective of contributing to the training of students in the public school system through

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prevention, promotion and health care actions. This inserts the Family Health Strategy nurse into the school environment, standardizing the partnership between health and education professionals[19].

However, it is known that the presence of school nurses is not a concrete reality in schools. The family, when taking the child to school, feels that during the period in which the children are in this environment they are unassisted, which can increase their situation of vulnerability (exposure of people to illness), involving a set of aspects not only individual, but collective and contextual[5].

In addition, the presence of nurses at school is necessary not only to provide care to students with chronic conditions, but also to act in disease prevention and health promotion, acting in school accidents, disease control, as well as in the actions of the health education[20]. The American Academy of Pediatrics published in a statement the recommendation of at least one nurse, full-time, in all schools in its country, since in the United States, children and adolescents spend many hours at school, thus generating several challenges for school systems, therefore they have several professionals in the area of education and health[21].

However, it is perceived with the participants of this study that this is not a reality in their lives. The school is not prepared to receive a child with special health needs, not even the school lunch is designed to meet their demands, family members reveal how difficult it is to maintain the child's dietary restrictions in the school environment. In this sense, it is extremely important to discuss food issues in the school context, as they are fundamental for the existence of human beings.

The school's difficulties in understanding the needs and limitations of these children can put their health at risk, as in the case presented here, in which the school is unaware of the implications of offering sweets to a child with diabetes. It is very difficult and extremely important to control the dietary restrictions of school-age children, and in diabetes this control is a crucial factor to avoid complications of the disease, it can also bring about an ambivalence of feelings, causing the child, on the one hand, to have the desire to eat certain foods, and on the other hand, they need to repress this desire[22].

The National School Feeding Program, of the Brazilian federal government, aims to promote healthy eating, through the offer of fruit and vegetables, with reduced sodium, restriction of sugars and industrialized foods, in addition to promoting good eating practices in students, favoring the permanence at school and the improvement of school performance[23]. However, as there are several dietary restrictions in the various chronic conditions, it is often unfeasible for the school to provide adequate food to everyone. This research presents information that shows weaknesses in the functioning of this program, exposing the situation of programmatic vulnerability to which

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these children are exposed, and in some situations, the family needs to provide the lunch.

From this perspective, the situations of vulnerability experienced by children with chronic conditions and their families permeate the three dimensions, however, an interaction between the individual vulnerability of families added to programmatic vulnerability is perceived. When the family does not have the financial means to send a snack to school, the child is left without food, as there is no social organization to meet this need.

In addition to food, it is also necessary to be aware of the care with devices used by children with chronic conditions, as in the case of the colostomy bag, in this study, as well as the need for tests such as capillary blood glucose and the use of medications. According to bill 6095 of 2016, the use of medication in any person must be judicious, since it is never risk-free[24]. In children, this care must be redoubled, as a wrong or untimely dose can cause from the aggravation of a disease to serious adverse reactions, including death. According to this law, the administration of drugs orally or topically to children under care in nurseries, day care centers and schools is authorized. However, this can only be done if a legible copy of the medical prescription is delivered to the school, containing, at least, the child's name, name of the medication, its dose and interval of use[24].

In this sense, it is necessary to consider that the technical knowledge for such procedures belongs to the nursing professionals, in this way, even a simple procedure such as checking capillary blood glucose becomes a great challenge for a professional without this skill, such as a teacher. The presence of nurses at school favors assistance to students, as well as providing support to educators, facilitating the inclusion of children with chronic conditions, contributing to comprehensive care, interventions and rehabilitation[20].

It was observed in this study that many family members fear the school environment exercising excessive protection, even if they recognize the importance of independence for their children, there is a concern to prepare the child to defend themselves from the gaze of society, which is often excluding and prejudiced[1]. The school context can be a complicating factor for the care of children with chronic conditions, and living with other children who are often unaware of restrictions that chronicity presents can negatively influence either through exposure to inappropriate foods or through questioning and criticism. about the condition of this child[25].

Thus, a scenario of bullying can be established, which leads to consequences such as low school performance, high stress level, revenge thinking, low self-esteem and low self-confidence. In addition, people who were bullied as children are more likely to suffer from mood disorders, such as depression and low self-esteem in adulthood[25].

In the individual axis, vulnerability is related to behaviors that can generate

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opportunities for situations of violence, such behaviors are subject to the action of objective, cultural and social conditions of the environment and the degree of awareness the person has about such behaviors[4]. The relevance of reflecting on how the child feels when starting a care routine is highlighted, which is mostly composed of limitations. At this juncture, the school can be positive in the child's life and also have negative effects on their life, due to the exclusion that sometimes occurs in the school environment. Even though the school is considered fundamental for the development and socialization of the child, in many cases, it can be seen as excluding, and organizational issues, such as the little structural and human preparation to receive children and adolescents with special health needs interfere with school inclusion[26].

Despite all the difficulties faced in the inclusion of children with chronic diseases in school, some family members reported about the help they receive from this service. The school is responsible for providing physical resources, but, in addition, it must value the individuality of children, without denying their limitations. In this way, the school context, when makes the partnership between family and school, enables the inclusion of children with chronic diseases. The articulation between parents and teachers favors the exchange of information about the needs of children with chronic conditions, enabling the development of strategies that contribute to care, the establishment of bonds and the socialization of these children in the school context, underpinning the inclusion process[7].

Finally, the importance of preparing schools and health services is highlighted, as well as the establishment of support networks between them in order to support children with chronic conditions and their families. In this way, the contribution to the child social development is favored, respecting their specificities and minimizing situations of vulnerability in their relationships with their peers and in carrying out their school activities[8].

FINAL CONSIDERATIONS

The study made it possible to know the family's perspective on situations of vulnerability experienced in the school inclusion of children with chronic conditions, which encompass the three axes: individual, social and programmatic. In this context, situations of vulnerability are intrinsic to human beings, which everyone experiences, whether to a lesser or greater degree. For the children's families, situations of vulnerability were accentuated after the child's illness, imposing a reorganization in the lives of all members. It is believed that through knowledge of components of these situations of vulnerability, health and education professionals can support the planning, evaluation and execution of care, in order to minimize these situations, expanding the autonomy of these families and their children, so that school inclusion is effective and provides

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the child's full growth and development, as well as their interaction with peers and the social environment.

The study brings contributions to the implementation of care by health and education professionals, thus requiring a close look at families/caregivers and their children with chronic conditions, aiming to provide them with the recognition of situations of vulnerability (individual, social and programmatic) that they experience, encouraging them to face these situations as citizens and providing them with a better quality of life. In this sense, it is essential to establish support networks between health service professionals, school and family.

As limitations of the study, it is pointed out the fact that it is not possible to interview other family members. Added to this is the difficulty in locating the families, because they reside in other municipalities. Furthermore, it is proposed that new studies be carried out, encouraging other professionals to continue investigating the vulnerabilities that families experience when faced with childhood chronicity. The care model for these families is expected to be rethought, thus understanding the needs of children with chronic condition and their families.

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